



Relatives' participation at the time of death: Standardisation in pre and post-mortem care in a palliative medical unit

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A B S T R A C T

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Purpose: The aim of this study was to illuminate the development of standardisation of relatives' participation at the time of death in the Palliative Medical Unit and to explore if the implementation of standardisation brought palliative care more in line with its ideology.

Methods: A registration form was developed and utilized by the Palliative Medical Unit nurse in charge of the patient and family to register to what extent relatives participated at the time of death. The study consists of two data sets named evaluation 1 and 2. Evaluation 1 includes data collected during the period 01.11.1995–31.12.1999, representing 73% of all deaths ($N = 244$). Evaluation 2 includes data collected during the period 01.01.2003–31.12.2009, representing 71% of all deaths ($N = 400$). The data was analysed in SPSS, covering primarily the frequency of participation and correlation between evaluation 1 and evaluation 2.

Results: Relatives are more often present at the moment of death, while nurses are less present at this moment. Additionally, Palliative Medical Unit nurses use more time to inform and discuss relatives' participation in pre and post-mortem care, as well as making agreements with relatives after death occurs.

Conclusion: Important premises for successful standardisation are fostering Palliative Medical Unit nurses' knowledge about various aspects of pre and post-mortem care through regular evaluation and an educational programme providing staff with necessary time, awareness and skills. In addition nurses also require sufficient amount of time in the clinic.

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Introduction

In this paper we describe the process of implementation of clinical practice guidelines over time in pre and post-mortem care in the oncological Palliative Medical Unit (PMU). The general aim of our paper is to determine if implementation of standardisation brought palliative care more in line with its ideology. Our main focus is relatives' participation at the time of death. In Norway hospital pre and post-mortem care has been criticised for excluding relatives (Wergeland Sørbye, 1994). In the wake of the hospice movement and with greater focus on palliative care in Norway, doors have gradually been opened and relatives invited to

participate. In fact, giving time and space to the family at the time of death of a loved one at Trondheim University Hospital PMU has become a standard procedure (Hadders, 2007, 2009, 2011). Nurses strive to involve the family in leave-taking events such as, 'the moment of death', 'laying out' of the deceased body, dressing, and viewing the deceased.

At the terminal stage and during post mortem care in the PMU, staff, patients and relatives are intrinsically linked to each other. At this time most patients are cognitively impaired, sleeping, in some cases sedated or biologically dead, and thus we are not dealing with patients' experiences, or patients' direct agency here.¹ The social identity, personal integrity and wishes of these patients depend on staff and relatives for safeguarding and maintenance (Hadders, 2011; Bremer et al., 2009; Hallam et al., 1999; Hockey, 2008;

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¹ Deep and continuous palliative sedation, so called terminal sedation, was given to approximately 1% of the patients in the PMU at the Norwegian hospital in question (Førde et al., 2008; Guidelines of the Norwegian Medical Association on Palliative Sedation, 2001).

Horne et al., 2012; Kabel and Roberts, 2003; Lawler, 1991; MacRae, 2010; Mossin and Landmark, 2011; Valentine, 2007, 234).

In Norway *The law on patient rights (Pasientrettighetsloven)* specifies who is to be considered next of kin (§ 1–3), and specifies the rights relatives have to obtain information about their relative's treatment in the clinic as follows (§ 3–3); 'When patients consent and when conditions vouch for it, the patient's nearest relatives shall receive information about the patient's health and the treatment given' (HOD, 1999a). According to the law patient's nearest relatives are persons defined as such by the patient. Norwegian health care is public and built on equity which entails equal access to services with the same standards and quality for all.

Palliative care and grief support: a brief background

For more than three decades there has been a steady growth of what Tony Walter called a revivalism concerning end-of-life care and death. In *The revival of death* (1994) he discussed the increased interest in death and dying that has emerged in the 'western' world. The application of this kind of revivalism has taken place mainly within the hospice movement and, more broadly within palliative care. The revivalist movement critiqued modernity and what it saw as the overly institutionalized, medicalized, de-humanized and technological way of dying within modern health care, leading to the disengagement of relatives (Illich, 1976; Moller, 1990, 2000; Seale, 1998).

The application of palliative care entails a clinical shift from cure to comfort. Central concerns within the hospice movement and palliative care are to control symptoms and to provide patients with an encompassing care which also includes relatives. Palliative care and medicine is a discipline which emerged as a logical extension and further development of the ideas within the hospice movement (Clark and Seymour, 1999; McNamara, 2001). The ideology of so called 'good death' has served as a central philosophical concern and standard within the hospice movement and palliative care (McNamara, 2001, 45–53). One of the elements of 'good death' in this context is fostering an open acknowledgement of the imminence of death, where the dying person is surrounded by family and friends (Clark, 2002, 907).

With greater focus on palliative care in Norway, relatives of the deceased are more often invited to participate at the time of death. In contemporary Norwegian society approximately 80% of the population die in hospitals or in some other type of health care institution. In 2012, 32.5% died in hospitals and 47.5% in some form of nursing home or other geriatric institution. 14.5% died at home and 5.5% died at other places (Statistics Norway, 2013). Mossin and Landmark report that 50% of cancer patients in Norway die in a hospital. The authors highlight the importance of relatives' presence when a patient is dying in the hospital (Mossin and Landmark, 2011).

At Trondheim University Hospital it has become standard practice to provide time and space for relatives at the time of their loved one's demise and the immediate aftermath of death. The procedure manual concerning the management of patient death on all wards at Trondheim University Hospital regulates the post-mortem care at the PMU (Hadders, 2009). In accordance with these guidelines, nurses generally attempt to include and accommodate relatives at the death watch of their beloved ones, at the time of death and at the subsequent viewing of the deceased. One of the driving forces for this practice standard, the wish to include relatives in leave-taking events, is to help relatives face the reality of death and assist them in their bereavement, in order for them to be able to accept the reality of death on their own terms. The tenet of grief support, anchored in palliative care ideology, is included in the general procedure

manual for death at Trondheim University Hospital (Hegvik et al., 2010; Mossin and Landmark, 2011; Walter, 1999; Worden, 1991). It is also included in a small information folder published by the Norwegian Directorate of Health, routinely distributed to all bereaved relatives by the nurses at the Trondheim University Hospital (Bergh, 2004:4). Furthermore, involving relatives at this time is also an outcome of the late-modern trend to celebrate the social identity of the deceased (Eschenbruch, 2007, 105; Hallam et al., 1999; Seale, 1998).

The aspiration to assist the relatives in their 'grief process' often hinges on a modernist understanding of a normal and proper universal grief pattern, which the mourners have to 'work through.' Since Sigmund Freud wrote *Mourning and Melancholia* (Freud, 1917), such 'grief work' has typically been understood to result in 'leaving the deceased behind', terminating the relationship with the deceased person. However, in recent decades the value of continuing the bond with the deceased has been increasingly documented and acknowledged by academics as well as in the clinic (Wortman and Silver, 1989; Walter, 1994, 1999). Several authors have underlined that the variety of rituals and actions following the death of a family member may contain aspects of separation as well as aspects of continuation of the social relationship with the deceased (Danbolt, 2002; Walter, 1999; Valentine, 2008; Hadders, 2011).

There is a growing body of research exploring relatives' experiences of being present at the time of death in the hospital setting. This research suggests that accommodative staff behaviour, emotional support and communication are fundamental to the experience and facilitates bereavement (Kwan Wai Man, 2002; Eriksson et al., 2006; Masson 2002; Donnelly and Battley 2010). Williams et al. underscore that family presence at the time of death of a loved one is a quality marker of end-of-life care. Among other things, they highlight keeping the family informed, providing reassuring attentiveness, being a compassionate presence, facilitating final acts of leave-taking and honouring the dignity of the deceased (Williams et al., 2012).

Theoretical approach to standardisation

Discussing standardisation in health-care, sociologists Timmermans and Berg point out that the etymological root of the word *standard* implies power; 'Originally a standard referred to a conspicuous object (such as a banner) carried at the top of a pole and used as a rallying point, especially in battle, or as an emblem' (Timmermans and Berg, 2003, 24). In other words, standards are ideals enforced in practice by legitimate agents. Generally Timmermans and Berg define standardisation as the process of making things uniform with various tools and policies. In their discussion they deal with the means as well as the outcome of standardisation. Standardisation in health care involves personnel with a legitimate mandate to implement certain clinical standards with the help of standardisation tools. Such standards are based on fixed criteria which safeguard a certain quality level of services rendered. However, it is important to underscore that the process of standardisation is not necessarily one-way and top-down. The dynamics of standardisation in process are complex. Timmermans and Berg argue that 'the generative power of procedural standards thrives on the local expertise the nurses and doctors develop in their interaction with these tools – and vice versa.' Standardization does not necessarily result in an obedient workforce, accomplishing their tasks in a rigid fashion (Timmermans and Berg, 2003, 78). Late-modern Norwegian standardisation of hospital death is embedded in material, social, legal, ethical, aesthetical and economical practices – at collective as well as individual levels.

Interdisciplinary negotiation and co-operation has opened up for a number of agendas to coexist when it comes to handling death (Hadders, 2009).

The study

Research setting

The PMU at Trondheim University Hospital was the first national competence centre of palliative medicine in Norway. Today this PMU is a regional competence centre and is situated within the Department of Oncology and Radiotherapy at this Hospital. The hospital is a 900-bed tertiary university hospital, a regional hospital for some 600,000 people and a primary hospital for about 250,000. The PMU consists of twelve single patient rooms, with an extra bed for family members in each room. The multidisciplinary team at the PMU consists of physicians, nurses, physiotherapist, social worker, nutritionist and a chaplain. In addition the PMU contains an outpatient programme with an ambulant section responsible for home visits, hospital patient consultations in other units at the hospital and consultations at the primary care services in local council within the region. Patients at the PMU are almost exclusively cancer patients with short life expectancy. The PMU does not admit patients under the age of eighteen. There are approximately 80 deaths per year at the PMU. Within the unit there is a communal room used, among other things, for social events, counselling relatives, commemoration events and viewings.

Development of research and standardisation tool

This research was originated and undertaken as a quality improvement programme. A standardized registration form with some twenty questions, initially named 'Routines at the time of death' has been developed and used by nurses. Petersvik (1997) underscored that the foremost purpose of the implementation of the form was to safeguard that relatives got the equal opportunity to participate at the time of death. Among other things PMU Nurses registered the time of death, those who were present at this time, what information and assistance relatives' were offered, how relatives' preferred to participate, if candles were lit in connection with the death wake, how the deceased was dressed, who were present at the viewing, if the deceased was placed in a coffin, and if the hospital chaplain was called for. In addition to registration, the tool has functioned as a guidance and checklist for nurses in connection with their interventions. Since 1995 nurses of the PMU has systematically registered relatives interaction with the deceased and with the healthcare staff with the help of this tool (Hadders and Torvik, 2003).

In 2003 a revised and extended version of the standardisation tool was implemented. The revised and extended registration form has been used in the PMU until 2009. The questions of the registration form appeared chronologically in the form, following the real time trajectory of the patient, in order to align interventions and registrations. The revised form was kept in the ward for about a month, before it was archived. The purpose of this was that it was used during post-death counselling with relatives.

Data collection and analysis

This study was undertaken as a quality improvement programme, using a descriptive study design. A standardized registration form has been used to register how relatives are informed and which activities relatives take part in when the patient dies. This tool has been filled out by the nurse in charge of the patient and family. Generally this nurse is one of two nurses who have been

following the patient and family since the time of admittance at the PMU (e.g. the primary nursing model).

During the year 2000 the Norwegian Cancer Society and Trondheim University Hospital funded a project which purpose was to evaluate the clinical practice with help of the data collected from the registration forms up until that time. This investigation involved 244 registration forms, representing 73% of all deaths at the ward during the inclusion period 01.11. 1995–31.12. 1999 (hereafter called evaluation 1). These results were published by Norwegian Cancer Society, in Norwegian, in the form of a report and some of the results were presented in a paper by first author (Hadders and Torvik, 2003; Hadders, 2011). In this paper we analyse the second batch of data collected during the period 01.01. 2003–31.12. 2009 (hereafter called evaluation 2). In total 438 forms were collected during this period. 38 forms were excluded from the study due lack of data due to incomplete registering by nurses. In some of the included registration forms some of the items were missing (number of cases = *n*). Although the number of missing items was relative small these nevertheless influences the reliability of the data. The data is analysed in SPSS, mainly covering frequency of participation. We also contextualize the data and compare corresponding items from evaluation 1 with evaluation 2. This comparison gives us some indication of how the standardisation of relatives' participation at the time of death in the PMU has change over time.

Ethical considerations

Permission to undertake this study was granted by the governing authorities at the Department of Oncology and Radiotherapy at Trondheim University Hospital. Approval from hospital ethical review comity was not required for this quality improvement study. All patient-identifying information was removed before the analysis to ensure anonymity. The study was reported to The Norwegian Data Protection Authority (*Datatilsynet*).

Findings

Our data is presented more or less chronologically as it appears in the registration form, clinical real time so to speak, representing the clinical trajectory of the patient in the PMU.

We loosely organise the data under three themes; information, relatives' participation, support given by nurses and interventions facilitated by nurses.

Information about signs of imminent death

Timing and information is crucial for nurses to accommodate relatives' participation. At the PMU, families are informed about, and made aware that the death of their loved one is drawing close. Some relatives camp at the ward and watch over their loved one throughout the final days or hours.

Standard procedure at the PMU entails that nurses inform relatives orally about common signs of imminent death. This practice has become well established over time. At the PMU these biomedical signs include the *Cheyne-Stokes* breathing pattern, diminished urine production, and poor peripheral circulation, which lead to cold extremities and discolouration of the body. To the experienced nurse, this combination of symptoms is a sure sign that the patient might die within days or even hours. Biomedical signs of imminent death play an important role when it comes to including relatives in good time and to make them aware of the fact that biomedical death is approaching. At this point the PMU nurses come to an agreement with relatives in what way and to what extent relatives likes to participate. They usually also come to an

agreement with relatives in what way they like staff to participate in the post-mortem care events. In 90% of the cases included in evaluation 2, relatives were informed about biomedical signs of imminent death. This represents an increase since evaluation 1. This find indicate that PMU nurses have gained an increased awareness of the importance of giving this vital information, an initial step in accommodating relatives.

Since evaluation 1, the registration form separates biomedical signs of imminent death from cognitive signs of imminent death. Cognitive signs include restlessness, cognitive impairment of various kinds and prolonged sleep. In 81% of the cases included in evaluation 2, relatives were informed about cognitive signs of imminent death.

There is a substantial increase in cases with an agreement about relatives' participation at the time of death from evaluation 1 to evaluation 2. PMU nurses more often inform and discuss relatives' and their own participation before death to enable relatives to participate on their own terms. Agreement about staff participation at the time of death was made in 80% of the case. This item was new in evaluation 2.

Relatives' presence at 'the moment of death'

The standard at the PMU is that no patient shall die alone (HOD, 1999b). As mentioned above, nurses make it a point to accommodate relatives at 'the moment of death'. In the context we are dealing with, biological death, 'the moment of death', is marked by the moment when patient's breathing stops. Relatives' presence at the time of death, with and without health personnel, has increased from 77% in evaluation 1–86% in evaluation 2. In evaluation 2 relatives were mainly the deceased's spouse and/or grown up children. Children under age of seventeen were present at 'the moment of death' in 6.5% of the cases and in 25% of the viewings in evaluation 2.

Health care personnel's presence at the time of death has decreased from 71% in evaluation 1–57% in evaluation 2. This indicates a considerable decrease in nurses' participation. One possible explanation for the decrease in nurse participation at 'the moment of death' is that PMU nurses have given sufficient information to relatives in advance and made the relatives secure enough to spend this time on their own with their loved one. There is no doubt that PMU nurses has gained an increase awareness about the importance to informing relatives prior to death in order to come to an agreement with them about relatives', as well as, nurses participation.

Relatives' presence and participation in post-mortem care

In the procedural manual concerning death of the patient in Trondheim University Hospital, nurses are empowered to reach an agreement with the relatives if: a) the relatives wish to wash or care for the deceased on their own or, b) if they prefer to do so together with the nurses or, c) if they just prefer to be present or, d) if they want to absent themselves during the laying out of the body (Hegvik et al., 2010). In accordance with these guidelines, PMU nurses generally attempt to include and accommodate relatives. Participating in the final care might involve combing, grooming, anointing, washing or dressing the body of the deceased. PMU nurses emphasize that it is important to inform relatives that participation in this post-mortem care does not necessarily entail taking part in all aspects of the entire care. They make it clear that relatives can help out with whatever small part they feel like, or just stand by and watch for some time. In this manner, nurses facilitate relatives' participation on relatives' terms. PMU nurses emphasize the importance of open

communication about the various aspects of the post-mortem care with relatives in reaching an agreement with them concerning their degree of participation.

At the PMU it is common to encourage relatives to dress their loved ones in private clothing, and in many cases relatives choose to do so for their final viewing after the moment of biological death. Most of the time the incentive to dress the deceased in private clothing comes from the nurses. As a part of their information about various aspects of post-mortem care, after the moment of biological death, nurses usually plant the idea with the relatives when they ask them if they had considered this option.

The results of the study show that relatives participated in the care after death in 18–19% of cases. This is a high degree of participation compared to other investigations in Norway and it important to underscore that degree of participation has remained constant over time. In Wergeland Sørbye's study of 90 cases of death at a nursing home in Oslo, relatives participated in 2 cases, e.g. in 2% of the cases (Wergeland Sørbye, 1994). In Danbolt's study of bereaved in Norway relatives participated in the laying out of the body in 10% of the cases (Danbolt, 2002, 47). PMU nurses' active communications with relatives have certainly played a crucial role in increasing relatives' participation over time (Hadders, 2011).

Relatives were informed about option to dress the deceased in private clothing in 89% of the cases and they chose to do so in 51% of the cases in evaluation 1. According to evaluation 2 relatives were informed about the option of private clothing in 96% of the cases. In 54% of the cases in evaluation 2, relatives chose to dress the deceased in private clothing for the final viewing. It has become a well-established standard to inform relatives about the option of private clothing and relatives more often chose to opt for this option.

When private clothing was not used, PMU nurses used hospital clothing (39%), or a small sheet or a pillow cover (4.5%), skilfully draping these over the deceased's shoulders and breast, covering the rest of the body with the bed sheet. Thus they create what looks like a ceremonial white death gown. The act of dressing the deceased in private clothing, encouraged by the PMU nurses, adds significant markers of social identity to the dead body.

The praxis of inviting relatives to relate to the dead body and dress it in private clothing mirrors the late-modern tendency for the body to become a central locus of the person's self-identity, albeit an embodied social life maintained by staff and relatives (Giddens, 1991; Shilling, 1993, 1; Twigg, 2000). In some rare cases the dying patient had informed relatives or nurses about the clothing she preferred to wear for the final viewing. However, it is clear that the responsibility for initiating the practice of dressing the deceased in private clothing at the PMU mainly has originated with the nurses.

Routines and rituals

Data from evaluation 2 shows that candles are lit in fewer cases before death. One explanation for this is that use of oxygen has become more common and that hospital fire regulations have become stricter. Candles are also lit in fewer cases after death. However, here the decrease is much less. A possible reason for this is that nurses defy fire regulations and continue to encourage candles to be lit as a form of leave-taking ritual (Danbolt, 2002). Data from evaluation 2 shows that deceased is placed in coffin in the ward in fewer cases. One reason for this is that undertakers no longer prefer to come to the PMU. In the new hospital premises undertakers have got their own facilities were they do their work and perform viewings, next to the hospital morgue. Data from evaluation 2 shows that written information of various practical and formal matters is given mostly after death (Bergh, 2004). A

possible explanation for this is that nurses have less time available to inform relatives about these matters prior to death of the patient.

Time in the ward from death to discharge

Within evaluation 2 the item total time of post-death period was only completed in 208 (52%) of the cases for various reasons. This item is of great interest in times when hospitals is demanded to be more cost-effective (O'Connor et al., 2005; Stuart et al., 2010). The shortest post-death period in the PMU was 1 h while the longest period was 39 h. The average time from death to discharge was 10 h (SD 6.7). The average time differ from 8.6 h when the patient died between 07.30–15.00 and 11 h when the patient died between 15.00–22.00.

Discussion

This study shows a number of changes in pre and post-mortem care at the PMU over time. When we compared the data batch of evaluation 2 with the data from evaluation 1 we found the following notable changes. Relatives are more often present at the moment of death and nurses are less present at this moment. PMU nurses more often inform and discuss relatives' and their own participation at the time of death with relatives and make agreements with relatives. Candles are more seldom lit before death and deceased patients are placed in coffin in the ward in only half as many cases. Written information about various practical and formal matters in the wake of death, advice about legal matters and undertakers, is given in fewer cases before death and more commonly after death. As mentioned above there are a number of likely reasons for these changes. Nevertheless, it is fair to suggest that the utilisation of the registration tool by PMU nurses have facilitated relatives' participation during post-mortem care and brought palliative care practice more in line with its ideology.

Regular clinical assessment and revision of the registration form is crucial in order to update and align procedural standards and ideology with clinical practice. In January 2000 a response group was founded at the PMU consisting of five nurses and a chaplain. One of the main goals of the revision of the registration form was to align the registration form closer to clinical practice. Another goal was to carefully reword questions and formulate the items in the registration form in a more open and less dictating manner. This revision process is yet another example of how the registration tool has been the driving hub for standardisation in pre and post-mortem care in the PMU. Regular registration, evaluation and revision help to propel and coordinate the standardisation process over time. Publications of registrations and documentation of evaluations also provide a valuable feedback and motivation for healthcare personnel. Timmermans and Berg describe the dynamics of procedural standards in use, and underscore that:

A proper (both effective and desirable) deployment of procedural standards creates a synergy between the staff members' embodied expertise and the tool's coordinating activity, in which expertise and coordination mutually reinforce each other. (Timmermans and Berg, 2003:78).

When procedural manuals originate within professions and are instigated by health care professionals this might lead to compliance with standardisation. Compliance with procedural manuals depends on the fit between ideology, goals, time at hand and demands upon health care personnel (Timmermans and Berg, 2003, 96). Noncompliance with the registration tool at the PMU, e.g. less utilization and registration, typically occurred during periods of

relocation of the PMU beds at holidays. During these periods administration of the registration form was handled by auxiliary stand in nurses or other nurses with little or no prior knowledge of the registration tool, and consequently often neglected (Petersvik, 1997). During construction of new hospital premises the PMU was relocated for a few years and less attention was given to the administering of the registration form.

Wergeland Sørbye has reported that Norwegian health care personnel have excluded relatives at the time of death (Wergeland Sørbye, 1994). Petersvik pointed out some possible reasons for the exclusion of relatives at this time. These where hindering attitudes, lack of experience and awareness amongst health care personnel, culture and traditions within contemporary Norwegian society, individual patients' wishes and relatives' culture and traditions (Petersvik, 1997, 46). The current anchorage for the participation of relatives at the time of death in Norway is based on an ideology founded in palliative care (Kaasa, 2007; HOD, 1999b) and the standards set by Norwegian national action programme for palliation (HOD, 2010).

As we have underscored above, ideals and written standards are not self-sufficient. Except for the entrepreneurial role of some health care personnel, it is important to highlight the additional premises which are crucial in the implementation of these ideals and standards in the clinic. These additional premises are dependent on allocation of financial resources for their implementation. In this paper we have mainly focused our analyses on the utilisation of the registration form, the central tool in standardisation of pre and post-mortem care. Additional important premises for implementation are fostering PMU nurses' awareness and knowledge about various aspects of pre and post-mortem care and legitimate time for nurses to inform, support and accommodate relatives (Kwan Wai Man, 2002; Eriksson et al., 2006; Masson 2002; Donnelly and Battley 2010; Mossin and Landmark, 2011). In fact, one of the most important factors controlling the quality of pre and post-mortem care is time at hand for PMU nurses. Considerable amount of time and resources is needed to prepare, support, accommodate and communicate with relatives.

In the papers *Palliative care work, between death and discharge* (O'Connor et al., 2005) and *After-death care and the hidden role of palliative care nurses* (Stuart et al., 2010) the focus of the authors is on the hidden nursing work during post-mortem care. The backbone for the discussion in these papers is the emphasis on time management and efficiency within hospitals in Australia. According to the authors, the lack of recognition of the complexity of post-mortem care and the time consuming nature of these nursing interventions are some of the main challenges in palliative care settings. The papers present and discuss the results of quality improvement studies of post-mortem care in two Australian palliative care units. The main aim of the studies was to determine the time required for post-mortem care through a one page questionnaire filled out by nurse. O'Connor et al. found that the average time between death and discharge was between 4 and 5 h. A major find from both studies was that most deaths occurred outside business hours with limited access of the multidisciplinary team. 'This reduces the capacity to spend time with patients and makes it more difficult to deliver quality and/or compassionate care, thereby increasing staff stress' (Stuart et al., 2010, 54–55). Limited access of the multidisciplinary team significantly impacted on the length of the time used for post-mortem care and increased nurses' workload. At Trondheim University Hospital the deceased remain a patient in the patient record system of the hospital, until the stage when the nurse has discharge them electronically. Interestingly, until recently, as the PMU nurses discharged the patient electronically, they back dated the time of the discharge from the ward to

Table 1

Data sets.

Data sets					
	Time period	Total number of persons who died at the ward	Number of registered deaths	Percentage of registered deaths	Age (mean/SD)
Evaluation 1	1/11 1995–31.12 1999	336 ^a	244 ^a	72.6%	68 (SD 12)
Evaluation 2	1/1 2003–31.12 2009	562 Male 56% Female 44%	400 Male 54% Female 46%	71%	66 (SD 12)

^a No registration of gender.**Table 2**

Information given to relatives, present at the time of death, relatives' participation in post mortem care, Routines and rituals.

Information given to relatives	Evaluation 1	Evaluation 2
Information about biomedical signs of imminent death	81.1% (<i>n</i> = 216)	90.1% (<i>n</i> = 343)
Information about cognitive signs of imminent death	–	83.2% (<i>n</i> = 220)
Agreement about relatives' participation at the time of death	62.3% (<i>n</i> = 190)	83.1% (<i>n</i> = 314)
Agreement about staff participation at the time of death	–	79.6% (<i>n</i> = 280)
Information about children and grief	–	40.8% (<i>n</i> = 294)
Present at the time of death		
Relatives present at the time of death without health personnel (mainly nurses)	23% (<i>N</i> = 244)	37.9% (<i>N</i> = 400)
Relatives and health personnel present at the time of death	54% (<i>N</i> = 244)	47.7% (<i>N</i> = 400)
Health personnel present at the time of death without relatives	18.1% (<i>N</i> = 244)	10.9% (<i>N</i> = 400)
Patient was alone at the time of death	4.9% (<i>N</i> = 244)	4.5% (<i>N</i> = 400)
Relatives' participation in post mortem care		
Relatives' presence and participation in post-mortem care	18% (<i>n</i> = 241)	19% (<i>n</i> = 397)
Information about the option to dress the deceased in private clothing	89% (<i>n</i> = 225)	96% (<i>n</i> = 375)
Use of private clothing for the final viewing	51% (<i>n</i> = 191)	54% (<i>n</i> = 378)
Routines and rituals		
Candle lit before death	98% (<i>n</i> = 116)	20% (<i>n</i> = 320)
Candle lit after death	99% (<i>n</i> = 204)	94% (<i>n</i> = 350)
Deceased placed in coffin in the ward	23% (<i>n</i> = 181)	11% (<i>n</i> = 316)
Oral information of various practical and formal matters after death	88% (<i>n</i> = 197)	90% (<i>n</i> = 296)
Written information of various practical and formal matters after death given to the relatives before death	34% (<i>n</i> = 197)	5% (<i>n</i> = 283)
Written information of various practical and formal matters after death given to the relatives after death	66% (<i>n</i> = 197)	95% (<i>n</i> = 283)

the time of 'biological death'. The reason for this backdating was that patient record statistics only concerned hospital treatment of living patients. As a result, the moment of death and the moment of discharge became the same. Thus, the actual care work nurses performed between deaths and discharge was not documented in official records.²

In evaluation 1, time of death was registered within two periods, simply by dividing 24 h in two equal periods; 20:00–08:00 with 51% of all deaths and 08:00–20:00 with 46% of all deaths. However, in order to represent the timings of the three nursing shifts at the PMU accurate, registration of time of death was divided into three periods in the revised registration from used in evaluation 2. In this way it is also possible to access nurses working load during the day within post-mortem care more accurately. The three nursing shifts are morning shift between 07:30–15:00 with 32% of all deaths, evening shift between 15:00–22:00 with 31% and night shift between 22:00–07:30 with 37% of all deaths. The majority of deaths take place in between 15:00–07:30 (e.g. 68%). During this period there is less support from the interdisciplinary team and fewer nurses on call. The most vulnerable period is the night shift with no support from the interdisciplinary team and few nurses on call. Over time PMU patients died alone in approximately 5% of all cases. Most of these instances were sudden and unexpected deaths. Some of these unattended deaths took place when no relative was present and staffs were fewer and preoccupied. In their overview of the initial years of clinical activities at Hospice Lovisenberg in Oslo,

Dahl and Wergeland Sørbye report that approximately 7% of the patients died alone (*N* = 344). Wergeland Sørbye notes that the ideal in Norway during the seventies and the eighties was that no patient should die alone. At this time it was common to hire extra staff that would stay next to patients during the patients' death wake. However, in spite of Norwegian national standard, due to financial and political changes within Norwegian health care management it is less common to hire extra staff today. Thus, Wergeland Sørbye underscore that it has become more common that patients die alone in hospitals and health care institutions (Dahl and Wergeland Sørbye, 2003; HOD, 1999b).

One of the more crucial additional factors which influence clinical practice is training and an educational programme providing staff with necessary skills and awareness about post-mortem care. In a multisite study Hill (1997) evaluated the quality of post-mortem care by nurses in the UK. Hill found that the lack of awareness and formal training in aspects of post-mortem care led to inflexible clinical practices and uncritical reproduction of senior role models' behaviour (Hill, 1997). In a review of the literature describing recently published research on preparing family members for the death of their loved one with advanced cancer Loke, Quiping and Leung recommend that a multidimensional educational programme should be developed for nurses and healthcare team members with the focus of preparing and supporting family members at the time of death. The authors 'envisioned that such a program will ease family members' bereavement process after the death of their loved one, decrease their risk for long-term psychological morbidity, and increase their well-being' (Loke et al., 2013). Skills and awareness is crucial and lead to more flexibility which enables nurses to improvise during pre and post-mortem care. Timmermans and Berg underscore that 'flexible

² This practice was changed in June 2013 when PMU nurses stopped back dating the time of discharge. Thus, the actual care work between deaths and discharge from the ward is now documented in official records.

standards' is not a contradiction in terms. On the contrary they claim that 'A standardised protocol's strength depends on the extent that the tool allows for deviation and improvisation ... A flexible procedural standard can be smoothly integrated in daily health care work' (Timmermans and Berg, 2003, 211). The goal at the PMU has been to initiate all nurses to the ideology, standards and practical use of the registration form within a compulsory educational programme for new employees. An introduction to background and ideology of the registration form is a prerequisite for a flexible utilization of the tool. However, in spite of this scheme the level of skills, knowledge and awareness of pre and post-mortem care amongst the PMU nurses still vary.

One limitation of this study is lack of documentation of relatives' response and feedback. Since 2003 the registration form was utilised by nurses to facilitate feedback and response from relatives during optional counselling meetings offered to relatives at the PMU, one month after death of the patient. The registrations served as a tool for nurses to initiate talk about the leave taking events with relatives. However, relatives' responses have not been systematically documented or published. In a future study, a design that enables the inclusion of relatives' views, response and experiences is desirable.

Concluding remarks

Standardisation of relatives' participation at the time of death in the PMU has been a nurse driven enterprise instigated and propelled by nurses. As we have demonstrated above '... the final product of the standardization effort crystalizes a perspective of the boundaries of professional expertise' (Timmermans and Berg, 2003, 116). We have illustrated how Norwegian PMU nurses strive to accommodate relatives in order to help them endure the burden of their sorrow and grief. Our findings and theory suggests that the standardisation tool facilitates relatives' participation. We therefore recommend a continuation of registration and the use of the tool.

In general Norwegian standardisation of hospital death is based on interdisciplinary co-ordination, communication and co-operation (Hadders, 2009). However, pre and post-mortem care includes mandatory as well as improvised tasks traditionally managed by nurses in particular. Historically nurses continue to have close contact with their dying and dead patients. They participate with patients and accommodate their families at some of the most intimate human events (Wolf, 1991, 92). Through the standardisation of relatives' presence at the time of death we have seen that PMU nurses accept this responsibility and this trust. Their goal, anchored in palliative care ideology, was to ensure that relatives got the equal opportunity to participate on their own terms. Tables 1 and 2

Conflicts of interest

None declared.

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